CASE STUDY

Supporting communication for parents with intellectual impairments: communication facilitation in social work led parenting meetings

Alison Matthews, Pennine Care NHS Foundation Trust, Oldhan, UK and Jois Stansfield, Faculty of health, Psychology and Social Care, Manchester Metropolitan University, Hathersage Road, Manchester, M13 0JA, UK (E-mail: j.stansfield@mmu.ac.uk)

Accessible summary

- Parents who have a learning disability have to go to meetings with professionals such as social workers and lawyers.
- Professionals do not always use easy words
- If someone helps professionals and parents to listen to each other, it is easier to understand what they are saying
- Listening and understanding is important for parents in meetings

Summary

People with intellectual impairments are recognised as having communication difficulties and even people with mild intellectual impairments can be challenged by complex language and limited literacy. The focus of this paper is parents who have learning disabilities, outlining a novel approach to support them in stressful case conference situations. Parents with intellectual impairments are frequently the subject of multiple interventions, case conferences and legal proceedings which challenge their communicative capacity. Case conferences often involve professionals with little or no experience of learning disability, including social workers and lawyers. The language in these case conferences can have complex sentence structure, low frequency legal vocabulary and difficult concepts, which are challenging for learning disabled parents to follow. The Communication Facilitator role is a recently developed approach to supporting parents in case conferences, aimed at enabling LD parents to understand and contribute to the proceedings. This paper reports the motivation and practical issues in developing the role, and the use of Communication Facilitator in child protection meetings where there are high stakes for not understanding, resulting in the potential removal of children from the parental home.

Keywords Family support, language issues, parents with learning disabilities, social services
Introduction

People with intellectual impairments are recognised as having communication difficulties (e.g. Enderby & Davies 1989; RCSLT 2010), and even people with mild intellectual impairments can be challenged by complex language and limited literacy (RCSLT 2010). The focus of this article is parents who have learning disabilities, most of whom have mild to moderate learning disabilities (Department of Health & Department for Education & Skills 2007). It outlines a novel approach to supporting them in stressful case conference situations.

Emerson et al. (2005) estimate around 7% of learning disabled adults in England to be parents and the Working Together with Parents Network (2008) suggested that the best estimate was that there was likely to be more than 53,000 parents with learning disabilities in England.

For many of these parents, their communication skills may have given little cause for concern previously (Stansfield 2012); however, the increase in communicative demand, for example the need to use a clock (necessary in order to feed their infant at regular times and to keep appointments); to read (in order to follow instructions on infant food packets, guidance on child care and many other types of literature); and to interact with a range of health and care professionals, can create many communication challenges.

Parents with learning disabilities are frequently assumed to have inadequate parenting skills (Booth et al. 2006; McGaw 2005; McGaw et al. 2010), even in the absence of evidence to support this view. Indeed, Stansfield (2012) reported case note entries where professionals clearly demonstrated their disapproval of behaviours which would give rise to little or no comment, if the parent was someone who had no intellectual impairment. As a result, however, many parents with learning disabilities find themselves involved with child protection procedures.

According to The Social Care Institute for Excellence (Social Care Institute for Excellence 2004) good communication is central to best practice in social work, but research with parents with LD and parents in general who are involved in child protection procedures has recorded parents’ feelings of exclusion and powerlessness (e.g. Booth et al. 2005; Kapp & Propp 2002; Thorpe 2008). Barriers to parents include a perception of not being listened to, a lack of active listening and poor communication by professionals and a lack of clear and specific goals which parents could work towards (Healy et al. 2011).

The communicative environment of parents with LD includes professionals who may have no experience, and no specialist training or knowledge, of LD (Booth et al. 2006; Ireland et al. 2012). Professionals include psychologists, social workers and solicitors, who can have a major impact of the lives of these parents and their children. When even support staff who are trained to work with adults with learning disabilities overestimate the comprehension levels of people with LD (Bradshaw 2001), it is likely that unfamiliar professionals will make similar assumptions about a parent’s communication skills. This is an important issue, as MacIntyre & Stewart (2011) suggest that the communication environment existing where there are concerns over parenting, can be a complex, fast moving and highly pressured experience for the parents and staff concerned. There is frequently little time allowed to prepare for meetings or to clarify legalistic paperwork. This combined with a lack of appreciation of the limits of communication ability (Bradshaw 2001; Stansfield 2012) can have a devastating effect on parents and their children (e.g. Booth et al. 2005).

LD parents can find themselves the subject of multiple interventions, case conferences and ultimately court proceedings. In these circumstances, professionals are routinely reported to use language which has complex concepts (e.g. ‘adequacy of parenting’, ‘suspicion of neglect or abuse’); low frequency vocabulary items (e.g. ‘inappropriate’ ‘non-compliance’); complex syntax in discussions; and frequent and rapid changes of topic (McConnell & Sigurjonsdottir 2010). Traustadottir & Sigurjonsdottir (2010) identify the difficulties which can be experienced by parents with LD if information is insufficiently modified to make it accessible. They describe the anxiety created by meetings, in which parents frequently struggle to understand and prioritise advice, which is itself frequently complicated and conflicting. This leads to the very real potential for misunderstandings and can have disastrous results for parents with learning disabilities (Booth et al. 2005, 2006).

In speech and language therapy practice, an increasing proportion of referrals are for assessments of young adult service users’ communication related to parenting ability (e.g. Stone & Howard 2009; Stansfield 2012). Speech and language therapists (SLT) working with adults with learning disabilities typically support communication through indirect methods (RCSLT 2010). They work with staff to increase communication opportunities, through staff recognising their own communication styles and modifying language levels as well as adapting living and working environments. This is recognised as good practice to enable LD adults to have optimum opportunities for communication (Bradshaw 2001; Kelly 2002; Kyle et al. 2009). In addition, other ‘reasonable adjustments’ (HMSO 2010) to reduce the impact of a person’s disability can include simplifying information so that it becomes more accessible (e.g. CHANGE 2013; Department of Health 2009; Tarleton & Marriott 2008). Figure 1 gives an example (original in colour), taken from clinical practice, which was produced with a parent with LD, who was the subject of concerns about her parenting. Here, a 37-page social work assessment was adapted by the first author and colleagues to enable this
parent, who had literacy and language difficulties, to understand issues and concerns about her parenting. Although the resulting chart is still quite detailed, the mother concerned reported that she now understood the concerns about her parenting and this has been demonstrated in her subsequent actions.

When concerns are raised regarding parenting, a social worker is allocated to the child or children concerned and depending on the severity of the concerns, an investigation may take place under section 47 of the Children Act (1989). The role of social worker is extremely demanding as there is a need to establish rapport with parents but also possibly to challenge parenting skills and decision-making, ultimately coming to a decision on action, based on risk. All this takes place within a timescale dictated by a legal framework, the common assessment framework (DfE, 2012). Locally, Gudgeon (2012) has presented these risks in a visual form (see Fig. 2). If the parent has LD, this can present a huge increase in complexity and extended delays to the process (Booth et al. 2006) and, as noted above, risks may be assumed simply because the parent has learning disabilities.

At a local level, if concerns are serious enough to trigger a child protection conference, a safeguarding and reviewing team (an additional team of social workers) becomes involved. The role of this body is to oversee the child protection, to plan and to chair case conferences. Core group which includes the child’s parents holds further meetings. The Core group reports back to the child protection conferences. Understanding the discussion at both types of meeting is imperative if parents are to have any influence on the decision-making process.

Forrester et al. (2008) propose the five aspects of good practice in child protection meetings, to be

- the use of empathy;
- care with the types of questions used;
- the use of reflections (which they explain as a hypothesis about what the client means or feels but expressed as a statement);
- the ability to raise concerns clearly;
- and finally the ability to balance this by a ‘recognition of positives and strengths’.

Healy et al. (2011) explored parents’ participation in child protection practice in the general population. They mention that parents identify a perception of lack of power and tokenistic participation. Other studies describe interactions as being adversarial (Hall and Slembrouck 2001) and with a focus on parents’ weaknesses (Budd et al. 2001). Kapp & Propp (2002) identified five problem areas, including poor

---

**Figure 1** Accessible summary of 37 page social work report.
or inconsistent communication; limited availability of staff due to worker turnover and overwork and a feeling of disrespect from staff. These added to a lack of involvement in planning and decision-making and a feeling their rights were not upheld. In this respect, Kapp & Propp (2002) describe parents being highly vulnerable when involved in the care system.

Unsurprisingly, parents with LD have similar experiences, describing child protection conferences as ‘harrowing and lonely meetings’, where they often did not know what was happening or the identity of the large numbers of professionals involved. Parents report feeling they are not listened to and being disempowered in ‘the formal atmosphere of overlong meetings’. (Tarleton 2007:135), and they were often unable to follow the discussion. This is also the authors’ experience of observing parents with LD in child protection meetings. Even after a parent has been assessed as having specific difficulties with understanding and/or expressive language, there is a challenge for the SLT in not only in raising this as an issue, but also in persuading colleagues, frequently under pressure and working to predetermined timescales, to adapt their practice.

**Communication facilitation**

The communication facilitator role was developed to directly address these concerns, by systematising the use of the five aspects of good communication described by Forrester, *et al.* (2007). In the authors’ clinical practice, parents involved in child protection proceedings have been exposed to complex language, competing priorities from professionals and a huge amount of advice, all presented verbally. Child protection meetings in particular are challenging places for people with communication impairments (MacIntyre & Stewart 2011). The high emotional demands of the situation can reduce the parent’s ability even to process information they would typically be able to understand. This is the impetus which led to the development of the communication facilitator role.

There is evidence that people with LD benefit from the use of picture-based material (Kelly 2002) and that people with LD have difficulties with literacy (Ward & Tarleton 2007). A Communication facilitator (CF) acts as a bridge between the professionals and parents in meetings and case conferences. In particular, The role of the facilitator is to slow the pace of communication in the meeting, clarify any unfamiliar vocabulary and produce a picture summary during the progression of a meeting, thus specifically promoting the areas of good practice identified by Forrester *et al.* (2007). Professionals’ use of positive as well as negative statements is encouraged during meetings by the use of two main questions, ‘what’s going well’ and ‘what are we worried about?’. The CF slows the pace by encouraging participants to sum up feedback from members of the

![Diagram](http://example.com/diagram.png)
meeting and encourages further reflection by supporting the parent to gain a turn and talk about their perceptions of what is going well and what they are worried about. Difficulties with prioritisation are tackled by the group as a whole and priority areas are negotiated explicitly with any support strategies identified.

The use of open versus closed questioning is debated in social work literature (Forrester et al. 2007), with a preference expressed for open questions. Adults with LD often require more skilled questioning, however, and sometimes closed questions are needed: the CF supports other team members to recognise when such questions are appropriate, while ensuring closed questions are not leading questions. The entire process is designed to enable the parent to have the optimal communication experience despite the difficult circumstances.

Local guidance for supporting people with LD in meetings tends to focus on setting an agenda, for instance in the ‘Guidelines for Accessible Meetings and Events’ (Disabled People’s Network Steering Group Community Network for Manchester’s 2005). Pearpoint (2002) and the North West Training and Development Team (www.nwtdt.com) have, for many years, also promoted an approach called ‘graphic facilitation’ within meetings. This approach is popular with staff; however, this style (as exemplified on the left of Fig. 3 below) is not easily understood by people with LD because of the demands it can put on visual perception, figure–ground identification, comprehension and (despite the Pearpoint’s reminder (2002) that ‘images are better than words’) literacy. The authors’ team has adapted the concept of graphic facilitation, using a style similar to the line drawings available from CHANGE (2013). Simple line drawings are produced on the left hand side of flip chart paper with writing on the right. This supports service users with LD, who may have very limited literacy skills, to understand the same complex concepts scanning from left to right and working down the page from top to bottom. This approach is also used by communication facilitators in part to simplify and in part to slow down the speed of meetings (see Fig. 3 below).

Discussion

Good communication is essential if parents with learning disabilities are to have any chance of understanding and contributing to child protection meetings. Staff, as the more competent communicators, hold the balance of power, and it is their communication styles which make the difference between a parent being included or excluded in decision-making (Healy et al. 2011). Staff are generally aware of good practice in meetings, but the demands of time and safety can lead to rapid, complex language which is well beyond the grasp of the parents concerned. This can be difficult and stressful for all concerned, in a rapidly moving environment when children are considered to be at risk. Good communication therefore needs to be systematised and supported. The CF role can help in reminding all participants of the need for effective communication.

The authors’ experience has been that in nonfacilitated meetings, parents are bombarded with a range of concerns of varying levels of severity with little transparency about the issues which need to be addressed as a priority. The communication facilitator role seems to increase the clarity over these concerns and supports the explicit prioritisation of any issues raised. There are a number of factors which may contribute to the effectiveness of the communication facilitator. The use of ‘what’s going well?’ as well as ‘what are we worried about?’ appears to result in an increase in empathic statements and positive comments, while still addressing areas of concern. The inclusion of the parent/s and family members by wording these questions accessibly and simply perhaps also provides opportunities for greater empathy as recommended by Healy et al. (2011). In addition, the fact that group members are asked to comment individually seems to change the perception of ownership of concerns, moving from the perception that it is the child’s social worker who has the concerns, to a collective concern and shared by all group members.

The use of simple line drawings (Kelly 2002) can provide an additional channel to support understanding and reduce the demands on limited literacy skills (Ward &
Tarleton 2007), while using accessible visual as well as auditory channels. Changes to group members’ communication have been noted by the first author when using this technique (drawing points on a flip chart). Changes include not only a reduction in professionals’ rate of speech, but also increased use of pausing, and simplification of the vocabulary used to describe any concerns. All of these adaptations are likely to support the service user’s ability to process the language (Kyle et al. 2009). Comments from social workers when a CF has been involved in meetings have been that it helps them to distinguish between a lack of understanding versus lack of compliance with the service user concerned. This is noteworthy as previously their reported impressions, supported by the literature (Booth et al. 2005, 2006; Traustadottir & Sigurjonsdottir 2010) had been that service users were typically seen as difficult and noncompliant rather than being confused, afraid and unable to understand.

McConnell & Sigurjonsdottir (2010) describe a number of key principles for practice in working with parents with LD in child protection systems including a view on communication. They advocate ‘ethically responsible practice demands that practitioners communicate with parents with intellectual disabilities in ways that they can understand’. They go on to say that ‘practitioners need to take the time to make sure parents understand the care and protection processes (an advocate or interpreter may be needed to assist) so that their ongoing participation in decisions that affect their lives and the lives of their children is assured’ (2010: 184–5). The CF role may appear to be one of simple advocacy; indeed, if best practice was always followed, the role may not be relevant, as all concerned in meetings with learning disabled parents would adjust their communication to enable the parents to be fully involved from start to finish. In practice, however, this does not often happen. As a result, this role can support parents and professionals to communicate with each other clearly, when they are making significant and potentially life changing decisions about a parents’ competence and a child’s safety.

References


© 2013 John Wiley & Sons Ltd, British Journal of Learning Disabilities